

Cultural Perceptions in Cancer Care among African-American and Caucasian Patients

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Purpose: This exploratory study examined perceptions and beliefs of African Americans and Caucasians related to cancer care. Understanding belief systems and cultures optimizes cancer treatment and care delivery to ethnic minority individuals.

Patients and Methods: Focus groups were conducted with 39 African-American and Caucasian cancer patients. Data analysis included whole group analysis with a team of five researchers.

Results: Regardless of ethnicity, cancer patients share many of the same emotions and experiences, and want complete information and quality care. Differences were also apparent. African-American participants were more likely to report increased religious behaviors, believe that healthcare providers demonstrate care with simple actions and provision of practical assistance, and use church and community information sources. Caucasian participants were more likely to report spiritual but not overtly religious changes, and depend on healthcare providers for information.

Conclusion: Understanding how culture colors perceptions, communication and information requirements is critical to providing effective care to ethnically diverse cancer patients. Findings have implications for professionals understanding ways patients seek information, the role of spirituality and religion in care, and ways healthcare providers demonstrate care.

Key words: African Americans ■ cancer ■ culture ■ attitudes and beliefs

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INTRODUCTION

Multiple studies have revealed disparities in cancer diagnosis and treatment within ethnic minority communities.^{1,2} Some reasons include poor communication and distrust,^{3,4} lack of appropriate and available information,^{5,6} and culture.⁷ Race and ethnicity are not the sole determinants of culture but are important components.⁸ Culture, as used here, is based on Bigby (2003), who defines culture as a “shared system of values, beliefs and learned patterns of behavior,” which includes racial and ethnic characteristics.⁹ African Americans have higher cancer incidence, lower survival rates and later-stage diagnoses than Caucasians^{10,11} and are 30% more likely to die from cancer.¹² This suggests that there are unique factors affecting the African-American cancer experience.

The need to understand effective provision of care to culturally diverse groups is supported by studies demonstrating the impact of cultural differences on providing care and comfort.¹³ This study used focus groups to explore belief systems, perceptions and needs of African-American and Caucasian cancer patients related to active cancer treatment and care.

METHODS

Sample

Participants were African-American and Caucasian adult outpatients diagnosed with any type or stage of cancer, except skin cancer, at an urban academic cancer center (Table 1).

Procedure

Physicians asked patients whether they wanted to participate in the study. Participants were enrolled in focus groups based on ethnicity to maximize similarities between participants to encourage open discussion.¹⁴ In qualitative research methodology, sample size may vary based on the phenomena of saturation. This is defined as when no new information is being elicited from additional participants.¹⁵ We reached saturation by the eighth group and ran three more to confirm saturation and to maximize

comparisons between groups. Focus group participants received a light meal, \$50 and travel vouchers.

Focus group interviewing is a sociological approach to collecting data that has its origins in advertising and marketing.¹⁶ It allows researchers to explore, via small-group discussion, psychological and sociocultural processes of the target group and is considered an excellent source of information about group norms and group assumptions.¹⁴ The most effective focus groups are comprised of a small number of participants, typically <7.¹⁷ The interaction between group participants produces data otherwise unavailable to the investigator during individual or even dyadic interviewing.¹⁴ We selected the focus group method as the best approach to the current study given the complexity of care for cancer patients.

To ensure consistency in topics, we used a moderator's guide, and groups were comoderated by investigators experienced with focus groups. Groups were audiotaped and material transcribed by a professional transcriber. Participant seating was charted and notes made on cues (such as volume, disagreement, nonverbal reactions) to track group evolution.^{14,16,17}

Sessions ran approximately 2.5 hours. Topics discussed included expectations for medical care, trusted sources for cancer care information, religion and spirituality, coping strategies, and sources of support. Most groups had ≥4 participants and three African-American groups had only two participants, as some participants were too ill to attend. Although this group size is not ideal, the analysis showed no differences in themes and we have chosen to include them here.

Over a period of 10 weeks, consent forms were mailed to 87 eligible patients with a return of 50 (57.4%). Of these, 34 (68%) were African American. Four (8%) withdrew from

the study due to severity of symptoms, and seven (14%) remained on a waiting list. Thirty-nine patients participated in focus groups: 23 (59%) African Americans participated in seven groups and 16 (41%) Caucasians participated in four groups. The study was approved by the Virginia Commonwealth University institutional review board.

Data and Qualitative Analysis

The focus of the analysis was to identify a range of topics and themes. Of five coinvestigators, three participated in all levels of analysis and two contributed to discussions about interpretation and provided reliability checks. To ensure a rigorous and consistent approach to the data, we kept detailed records. The focus groups were analyzed using whole group analysis with each group-1 data unit.¹⁵ Groups and themes, not individual participants, were compared. We charted data from verbatim transcripts, using data matrices for each group and comparing to other groups. Each investigator read the transcripts multiple times, made clarifying notations, and identified specific topics and themes. We then compared notes, recorded each investigator's identified topics and themes, and examined concordant and discrepant interpretations. Overall, interpretations were highly concordant, although we did not measure specific levels of agreement among the coders. Investigators discussed differences, when identified, and came to consensus on coding.

Different data sources (triangulation) were used to ensure reliability and validity.¹⁵ These sources included a process observer and participant checks. We conducted participant checks by contacting focus group participants to review our interpretations with them and determine whether our assessment was consonant with their experiences. We addressed intrarater and interrater reli-

Table 1. Characteristics of the participants (N=39)

	African American		Caucasian	
Total Focus Groups	(N=7)		(N=4)	
Total Participants	(N=23)		(N=16)	
	Number	Percentage	Number	Percentage
Female	19	83	10	63
Income <\$10,000	9	39	8	50
Employed	7	30	6	38
Between Ages 40–59	14	62	9	57
Uninsured	2	9	9	56
Type of Cancer				
Breast cancer	13	57	5	31
Colorectal cancer	4	17	3	19
Lung cancer	1	4	2	13
Hematologic malignancy	2	9	1	6
All other cancers	3	13	5	31
Status at 10-month follow-up				
Deceased	2	9	3	19
Lost to follow-up	1	4	1	6

ability by keeping coding records and developing a code book, using matrices, having ongoing discussions within the team and reviewing interpretation with other experienced researchers, thus enhancing reliability and reproducibility in the coding. Atlas Ti® software was used to help with analyzing data. Primary themes were identified by frequency of mention across groups and analyzed to determine overlap and divergence between groups.

RESULTS

Commonalities of Themes

Findings suggest that, regardless of ethnicity, cancer patients have many similar experiences and feelings when facing cancer and undergoing treatment (Table 2).

Changes in Self

Participants in all groups described changes experienced as a result of having cancer. These included performing fewer obligatory activities, seeing people and the world in new ways, changing negative behaviors, and repairing or discarding relationships. One African-American participant said, "I went salsa dancing last night. [I'm] trying to find ways to enjoy my life differently by doing things that I want to do." A Caucasian female noticed small details of life: "I saw my first real live woodpecker and all the colors on it. I don't think I would have ever paid attention to it before I was diagnosed."

Several participants talked about changing negative behaviors as a result of the cancer diagnosis. A young African-American male said, "It's funny how life works ... like with some of the stuff that I was doing I would have been in like a lot of trouble right now if [cancer] would not have happened to me." Similarly, a young Caucasian male said, "I think that if this cancer had not hit me when it did that I was just going down the wrong road. It certainly woke me up." Other participants stopped drinking and smoking, exercised more, and talked more to family or friends.

Coped by Talking with Others

Most participants coped with cancer by talking with others. An African-American male compared his situation

with others: "Just talking to other people about my experience with the cancer helps me." Some talked about their cancer and discovered others also had experienced cancer. As an older Caucasian female, "The more people I told, the more I would hear about other women who had had this, and that was really helpful."

For some, the goal was to educate or help others. An African-American female with late-stage disease saw it as something of a legacy she could leave:

You can say, 'Well, I remember my friend, D, when she was going through the same thing. Let me tell you how she told me she got through this.' That could help somebody else. I may not be here to tell that person myself.

A Caucasian participant said, "I feel like it could help somebody else to go through what I went through, so they won't be so scared."

Participants spoke mostly with family and close friends or other cancer patients. Some participants felt they had no one or felt talking was not helpful. One Caucasian male commented, "When you have nobody you have to be your own support and that, to me, has been the hardest thing of this." For one African-American female, talking was not useful, "Cancer is not in our conversation. It's not that you are denying anything, but talking about it is not the answer." For another it was not acceptable, "It's a taboo still connected with having cancer and we still hide from having people talk about it." Participants said it was lonely when family did not understand their experiences.

Death was discussed in all the groups. Participants said talking about this topic was difficult, "You tell somebody you got cancer and they think, 'oh she's gonna die.'" Terminally ill patients felt isolated. An African-American female with metastatic cancer said, "Some people, if you talk to them about death, they don't want to hear it." An elderly Caucasian male, on the other hand, insisted on talking about it, "I talk about my death and my demise. We spend all our life living but we don't spend 20 minutes thinking about dying."

Table 2. Commonalities between ethnic groups

	African-American Focus Group	Caucasian Focus Group
Total Focus Groups	(N=7)	(N=4)
Theme	# (%)	# (%)
Changes in self	7 (100)	4 (100)
Coped by talking with others about experiences and feelings	7 (100)	4 (100)
Information: wanted additional information (about disease, treatment, decision-making, side effects, financial and legal issues, and/or support services)	7 (100)	4 (100)
Wanted medical providers to keep patients informed	6 (86)	4 (100)
Had financial problems as a result of cancer	6 (86)	3 (75)

Information Preferences

There were similarities between groups and differences among individuals on how informed they wanted to be about cancer prognosis. A Caucasian male said, "I want to know everything upfront and I can handle it," and a Caucasian female said, "If I found out today that I only had two years left, my whole life would change ... it would crush me."

All groups had participants who wanted physicians to keep them informed and complained that physicians sometimes withheld information about side effects or test results. Very few participants wanted to know little or nothing about their cancer, treatment and prognosis.

Financial Problems

Diagnosis and treatment of cancer appeared to have a substantial financial impact on many participants, particularly those who had jobs prior to diagnosis. One participant described getting a legal separation from her husband to be eligible for benefits. Others who had to leave work found gaps in income and could not find support systems, as an African-American female discussed:

They say to call this agency and call that agency, but you can't always get that financial support that you need ... They really don't have anything for people who are working and fall into hard times.

A Caucasian female also said,

I get frustrated that they don't consider chemotherapy or cancer a disability until you can't move ... I mean if you can't work for six months, I would consider that a disability.

Similarly, an African-American male reflected on the expense of care and said, "Where am I going to get \$600 to pay for the medicine?" Examples of financial difficulties included borrowing money to pay a mortgage, not being

able to pay utilities and selling a truck to pay for medical out-of-pocket expenses. Finances did not seem to affect patients' adjuvant therapies; however, this cancer center provides care to all state residents regardless of ability to pay.

Differences in Themes

Cultural differences also were apparent (Table 3). While participants of both ethnicities were supportive of other participants in their focus groups, African-American participants generally showed higher engagement with other group members, used each other as information sources and verbally validated each others' comments. In all but one African-American group, participants gave each other personal contact information and made arrangements to see each other again outside the focus group, which did not happen in any of the Caucasian groups. African-American participants also referred more to wanting information and described faith and church families as part of their support and information systems.

Religion and Spirituality

All participants who described themselves as "religious" before diagnosis remained religious after diagnosis. African-American participants talked about increased faith and church attendance after diagnosis, and used church, faith and church families for coping and receiving support. Related quotations include, "That was a wake-up call for me with the Lord when that happened because I just started talking to Him," "Now I go [to church] every Sunday and I even go to meetings on Wednesday nights," and "It just changed me and I started to pray more and read the Bible more and listen to more gospel music."

Participants in six of seven African-American groups spoke about the significance of prayer in helping them cope with their cancer diagnosis, treatment and recovery. The significance of prayer and their faith communities was addressed by participants in two Caucasian groups. A strong difference seemed to be that the faith community often initiated and facilitated prayer for Af-

Table 3. Differences based on ethnicity

	African-American Focus Group	Caucasian Focus Group
Total Focus Groups	(N=7)	(N=4)
Theme	# (%)	# (%)
Religiosity		
Described increased religious behaviors or faith (e.g., attending church, praying and requesting prayers, asking for assistance from church members)	6 (86)	1 (25)
Used terms "spiritual" and "spirituality" to describe religious activity	0	3 (75)
Ways Healthcare Providers Demonstrate Care		
By showing emotion and concern	7 (100)	1 (25)
By providing practical assistance (e.g., food, escorting to ER, blankets)	6 (86)	0
Information Sources		
Depended on family, friends and community for cancer information	7 (100)	1 (25)
Saw physician as primary source of information	1 (29)	2 (50)

frican Americans describing this form of support. The authors describe this in detail in a separate paper.¹⁸

Caucasian participants were more likely to use the terms spiritual or spirituality to describe faith or religion. Related quotations include, "I am not into a bunch of religion. Spirituality is between me and God," "I don't trust any sort of group religion," "When it comes to my spirituality it is only about me," and "My beliefs don't fit into any sort of organized religion or anything like that." Only one Caucasian participant talked about going to church more frequently after diagnosis saying, "I started going to church every Sunday."

Ways Healthcare Providers Demonstrate Care

All participants discussed ways that physicians and nurses demonstrated care for patients. Provider behaviors that were most often described included keeping patients informed and explaining about disease, treatment and procedures. Of value to most participants were physicians who gave them time, were sincere, answered questions, were honest, returned calls and demonstrated positive attitudes. African-American participants also described showing genuine emotion as an example of healthcare providers demonstrating care. One female participant said, "They really care. If you cry, they cry."

Trust of physicians and the medical environment was an issue in several African-American groups. One male participant said, "If you can't trust your doctor, then you can't feel safe with your doctor, or for that matter, feel safe in the facility that you come to," and a female participant responded by saying, "Their first 5–10 years they are there to help people, but after that they only think about that money." A number of African-American participants also said that they were surprised by the level of attention and care they received in the oncology clinic and the hospital, as reflected in a male participant's comment, "I appreciate the fact that my doctor goes out of her way and I feel real good about her . . . I was just surprised by that."

African-American participants also described specific actions as meaningful, such as one oncologist escorting a patient to the emergency room, another giving away a blanket and a treatment team celebrating a patient's birthday.

Information Sources

All participants saw physicians as one source of information, although not necessarily the primary source. African-American participants were more likely to talk about going to family, friends and their community to learn more about their cancer and what to expect with treatment. Caucasian participants were more likely to describe getting information from physicians, the American Cancer Society and the Internet. Participants in all groups talked about wanting complete information from physicians and nurses, although some felt their questions were not sufficiently answered. Participants also

described receiving and using written materials. Some had difficulty reading or understanding the materials and not everyone found the materials helpful.

DISCUSSION

Regardless of ethnicity, participants described many of the same emotions and experiences, and wanted complete information and quality care. Differences between ethnicities included religion and spirituality, perceptions of how healthcare providers demonstrated caring and information sources. This has implications for providing care to ethnically diverse populations.

African-American participants focused more on religious behaviors, whereas Caucasian participants talked about spirituality rather than religion. Given that African Americans may be more explicit in referencing religion as a resource for managing or coping with the diagnosis, providers should be prepared to respond to or support the use of this resource. Providers need to be sensitive to differences between religious practice associated with a specific doctrine and spirituality. Providers can reference religion and spirituality as means of coping with cancer while also providing other options.

African-American participants described specific caring actions as being meaningful to them. These actions included physicians and nurses showing emotion and concern for them as well as providing practical assistance, suggesting several ways to enhance patient-provider trust, patient satisfaction and quality of care by simple acts of kindness. Caucasian participants did not describe similar actions. This could be because they expected these behaviors or simply discussed other types of interactions (e.g., exchanging information) that were of higher priority for them.

How provider actions may have affected treatment was not addressed. Of 39 participants, only one individual described missing treatments. However, multiple factors, such as limited health literacy, depression, denial and transportation problems, appeared to contribute to his poor treatment adherence.

Patients undergoing cancer treatment must continuously gather information, make sense of technical and complex details about cancer and cancer treatment, communicate with medical and lay persons, and make multiple decisions. Even when patients are capable of understanding higher-level material, most still prefer to receive simplified reading materials.¹⁹

Health literacy (i.e., accessing and understanding health information)²⁰ is of considerable importance for patients managing their healthcare. Our findings confirmed that health literacy is a challenge for all patients. Participants commented that written materials were available but not always helpful. They suggested that these materials be supplemented with other types of communications. This finding is consistent with evidence that culturally congruent communication and simplified materials are necessary components of medical care systems seeking

to improve health outcomes and reduce disparities.^{19,21}

With regard to sources of information, African-American participants depended more on family members, friends and community for information about their cancers, whereas Caucasian participants saw physicians as primary sources of information. The fact that African Americans described using faith communities for information and support suggests that alliances with religious organizations could be an effective way to disseminate information. Previous research indicates that community channels such as this could expand outreach.^{22,23}

Implications for Clinical Practice

Our study suggests that patients would value additional support and information. Useful medical information includes common symptoms and side effects and ways to treat them, disease progression and details about specific cancers. Practical, legal and financial topics of importance include applying for public benefits and other financial resources; negotiating with insurance companies; preparing wills, powers of attorney or healthcare directives; and communicating with employers. Additionally, information about common emotional reactions and sources available for personal support could be useful to patients undergoing cancer treatment.

Several ways to provide this information are:

1. Free workshops featuring experts in different areas (e.g., medical, financial, legal, psychological).
2. Videos presented in reception areas or treatment rooms with information about coping, common side effects, financial resources and other pertinent information.
3. Providers initiating conversations about how cancer diagnosis and treatment might affect patients financially, emotionally and spiritually.

Limitations

This study was an exploratory study conducted at one cancer center with a high concentration of minorities and patients with low SES. Participants were primarily African American and female, which allows common issues and concerns to be voiced but limits the generalizability of findings. Different themes may have been emphasized in mixed ethnic groups. There may be differences specific to cancer site and stage that were not identified. While it was not ideal to have three sessions with two participants in each, we believe the information gathered was valuable.

Focus groups are useful in learning about group norms, but group dynamics can affect the nature of discussions. Just because issues were not discussed in a group does not mean that these issues did not exist for participants.

CONCLUSION

Patients want complete information and kindness regardless of ethnicity. Understanding how culture colors

perceptions, communication and information requirements is critical to providing effective care to ethnically diverse cancer patients. This qualitative study demonstrates the need to recognize and explore cultural beliefs and values in persons with cancer.

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